

The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned

C. CHRISTOPHER HOOK, MD, AND PAUL S. MUELLER, MD

The recent case of Terri Schiavo has been an important medical, legal, and ethical controversy. However, much of the public discussion of the tragedy has been based on inaccurate information regarding the facts of the case and the actual legal and ethical issues involved. This article reviews the pertinent aspects of the case and the ethical and legal questions raised and highlights the lessons we should learn from this unique story.

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AFN = artificially supplied fluid and nutrition; LST = life-sustaining treatment; MRI = magnetic resonance imaging; PEG = percutaneous endoscopic gastrostomy; PVS = persistent vegetative state

On March 31, 2005, a 41-year-old woman, Theresa Marie Schiavo (born December 3, 1963), died, the final complication of a cardiac arrest on February 25, 1990. Her illness and death had been the focus of a major medical, legal, theological, ethical, political, and social controversy, a controversy that continues. While other issues, such as the controversy over embryonic stem cells and cloning, generate significant discussion and debate, the plight of Terri Schiavo is the most important case of clinical ethics in more than a decade. The results of this case threaten to undo at least 30 years of ethical and legal progress that has enabled individuals the freedom to control and limit medical interventions performed on them. The case also highlights the deep divisions and fears within our society regarding life and death, the role of the government and courts in life decisions, and the treatment of disabled persons.

A hallmark of the Schiavo case is the confusion surrounding the facts and operative questions. Was she in a persistent vegetative state (PVS) or a minimally conscious state?¹ What, if any, hope of cognitive recovery did she have? Are these questions relevant to the due process of decision making in this case? What were the events surrounding Terri's cardiac arrest that caused her brain injury? What were Terri's previously expressed wishes regarding life-sustaining treatments (LSTs) for situations such as

PVS and in which she could not make decisions for herself? What is the role of the courts in adjudicating uncertainty and familial conflict? What are the duties of surrogate decision makers? Do they have specific obligations? Is PVS a disability or a life-threatening pathology? Is the provision of artificially supplied fluid and nutrition (AFN) mandatory humane comfort care, or is it a medical intervention that can be refused, withheld, and/or withdrawn? Did Terri suffer during the process of dehydration?

Numerous aspects of this case will never be clarified. Future students will be forced to contend with inadequate or incomplete information, just as we who have followed the case contemporaneously have had to do. However, there are sufficient facts for us to learn from this case, lessons that are critical to our patients, our practices, and our society. In this article we attempt to bring as much light as possible to a case shrouded in misinformation, inadequate reporting by the media, and misleading claims and pronouncements made by public figures about the patient, her condition and prognosis, and the ethical and legal issues in the tragedy. We hope to objectively answer some of the aforementioned questions but acknowledge at the outset that we cannot address them all. Our goal is not to pass moral judgment on the individuals involved directly in the case—something we cannot and will not attempt to do—but to try to provide objective information and understanding in the hopes of stimulating rational discussion and much needed healing to our society. We also acknowledge that there are people of good will on the many "sides" of this issue, individuals who sincerely hold deep beliefs divergent from one another. We cannot resolve all these disagreements but wish to at least help to ensure that the ongoing discussion about this case is based on as much fact as possible.

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A BRIEF HISTORY

Because our goal was to review and evaluate the facts of the case, rather than depend on the incomplete reporting in the lay press, we tried to access as many primary documents of the proceedings as possible. An excellent source was the Web site created and maintained by Steven Haidar and Kathy Cerminara at the University of Miami,² which not only provided an excellent and thorough timeline of the

From the Division of Hematology (C.C.H.) and Division of General Internal Medicine (P.S.M.), Mayo Clinic College of Medicine, Rochester, Minn.

Address reprint requests and correspondence to C. Christopher Hook, MD, Division of Hematology, Mayo Clinic College of Medicine, 200 First St SW, Rochester, MN 55905.

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events but also provided links to original reports, judicial decisions, and some of the testimony presented during the court proceedings.³ We were unable to directly access Terri's medical records and consequently had to depend on the summations of that information as recorded in various legal and court documents.

On February 25, 1990, then 26-year-old Terri Schiavo fell unconscious in her apartment in St Petersburg, Fla. Her husband of 5 years, Michael Schiavo, called the paramedics but did not perform cardiopulmonary resuscitation. Terri was anoxic until help arrived. She was resuscitated but never regained consciousness, and a percutaneous endoscopic gastrostomy (PEG) tube was placed to provide nourishment and hydration. It has been stated that the cardiac arrest was precipitated by an electrolyte imbalance, given that her first potassium level obtained in the hospital after resuscitation was only 2.0 mEq/L (reference range, 3.6-4.8 mEq/L). The hypokalemia has been said to be due to anorexia concurrent with attempts of assisted reproduction procedures, but given that the potassium assay was performed after her resuscitation, the actual cause of Terri's cardiac arrest remains unresolved.⁴ The police were called to investigate the situation, but the reporting officers found no evidence of physical struggle or abuse in the apartment, nor was any present on Terri's physical examination.⁵ (At Terri's autopsy years later, the only sign of bony irregularity was a vertebral compression fracture due to severe osteoporosis, which was likely due to her prolonged bedridden state, and there was no evidence of previous fractures, tracheal injury, or other signs of trauma.⁵ Despite a reexamination of the events surrounding the original event requested by Governor John Ellis [Jeb] Bush, prosecutors Doug Crow and Bob Lewis could find no credible evidence of physical trauma or abuse, nor of any wrongdoing by Michael Schiavo.⁶ Governor Bush subsequently closed the inquiry.)

After several weeks, Terri was transferred to a skilled care and rehabilitation facility. Because there was no advance directive, Michael was appointed Terri's formal guardian on June 18, 1990, by the court. Terri's parents, Robert and Mary Schindler, did not object to this appointment. In the hopes of bringing Terri home for her care, Michael received some nursing training; however, an attempt at home care in September 1990, provided in the Schindlers' home with Michael in residence, proved too overwhelming, and Terri was returned to the chronic care facility after 3 weeks. Two months later, Michael took Terri to California to pursue experimental thalamic stimulator implant treatment to improve or restore her level of consciousness. The treatment failed, and they returned to Florida in January 1991; Terri was placed in the Mediplex Rehabilitation Center in Brandon, Fla. Numerous neuro-

logic evaluations revealed only reflexive behaviors consistent with a PVS. Multiple swallowing studies showed severe oropharyngeal dysphagia, but Terri continued to receive intensive physical, speech, and occupational therapy.

Michael continued to live in the Schindler home for several more months until May 1992. According to the report by the third guardian ad litem (a court-appointed individual who is an advocate for and represents the best interests of the ward) appointed during subsequent court trials, Michael was fixated on Terri's care for the first 4 years after her cardiac arrest. The Schindlers encouraged Michael to move on with his life and to start dating. Michael, in turn, would introduce the women he was dating to the Schindlers.³ In 1994, Michael appeared to have changed his belief that Terri would recover to the belief that she would never improve. He elected to not treat a urinary tract infection that had developed and requested that Terri's status be changed to "do not resuscitate." When the facility challenged this, Michael rescinded the requests but subsequently transferred Terri to another facility.

The relationship between Michael and the Schindlers deteriorated in 1992 after he and Terri were awarded damages in 2 malpractice suits (regarding her infertility treatments and a possible association with her subsequent cardiac arrest): the first for \$250,000 and the second for \$300,000 to Michael for loss of consortium and \$750,000 to a trust fund for Terri's care (the trust fund was controlled by South Trust Bank, not Michael). Several claims have been made about the cause of the breakdown in the relationship between Michael and the Schindlers (arguments regarding plan of care, anger because Michael did not share the malpractice award with the Schindlers, etc), but the complete truth will probably remain unknown to the outside world and ultimately is not relevant to our discussion. The result is that on July 29, 1993, the Schindlers petitioned the court to remove Michael as Terri's guardian. Because no basis was found for such removal, the suit was dismissed. The findings of the first guardian ad litem appointed in the case, John H. Pecarek, were that Michael had been very aggressive and attentive in his care of Terri. Noting no evidence for infections or skin breakdown and referring to reports of tirades by Michael that would bring nurses to tears if Terri's care was not performed meticulously, Pecarek stated in his March 1, 1994, report, "Although I have concluded that Mr. Schiavo is a nursing home administrator's nightmare, I believe the ward (Terri) gets more care and attention from the staff...as a result of his advocacy and complaining on her behalf."⁷

Four years later, in May 1998, Michael petitioned the court to authorize the removal of Terri's PEG tube. Be-

cause the Schindlers opposed this petition, claiming that Terri would have wanted to be kept alive, the court appointed a second guardian ad litem, Richard L. Pearse, to serve on behalf of Terri's interests. In December 1998, Pearse issued his report, which noted that Terri was in a PVS and, according to her treating physicians, had no chance of improvement. Pearse believed that the only evidence of Terri's wishes concerning LSTs was hearsay evidence from Michael, which did not, in his mind, present the clear and convincing evidence standard required by *In re Guardianship of Browning* precedent and Florida State Law (see subsequent discussion). In addition, Pearse suggested that Michael may have had a significant financial conflict of interest.⁸ Pearse stated, however, that "In fairness to the Petitioner, should this Court disagree with the foregoing analysis of the evidence and find it to clearly and convincingly reflect the actual wishes and intentions of the ward...the feeding tube should be withdrawn."^{8,9}

On January 24, 2000, the trial to determine Terri's wishes began in the Pinellas-Pasco County Circuit Court under the direction of Judge George Greer. Presented to the court were depositions from Michael and from Michael's brother and sister-in-law recounting statements made proximate to family funerals and in other conversations in which Terri had stated she would not want to be maintained on artificial life support should she become seriously ill and dependent on such measures to maintain life. On the other hand, the Schindlers indicated that, if Terri had provided clear directives that she would not want to be maintained on artificial life support while in a PVS, they would still insist that she be given all treatment and life support possible.¹⁰

Among the testimony heard was that of Father Gerard Murphy, from the diocese of St Petersburg and the State of Florida chaplain for the Catholic Medical Association. Father Murphy stated that removal of the feeding tube from Terri would be in keeping with Roman Catholic teachings provided that Terri had mentioned to her husband and to her brother and sister-in-law that she would not want to be kept alive artificially if she were dependent on the care of others. Father Murphy also stated that, given the fact that Terri had not received Communion or participated in confession for at least a 2-year period before her medical event, she would not be considered a practicing Catholic. When asked about the Schindlers' assertions that if they were in a PVS or unconscious state without hope of recovery that they would want all medical treatments and procedures possible to keep them alive, even to the extent of amputations in the case of gangrene or that would result in the impoverishment of their family, Father Murphy replied that the Catholic church had no such vitalistic requirement. Regarding the claims of the Schindler family that Terri

should be kept alive because it gives them pleasure, regardless of the extent of life support or disfigurement by necessary amputation, Father Murphy stated that this was contrary to the Gospel and to the teachings of Christ and the Catholic church.¹¹

Judge Greer issued his ruling on February 11, 2000, granting the removal of the PEG tube. He stated,

The court does find that Terri Schiavo did make statements which are creditable and reliable with regard to her intention given the situation at hand....Statements which Terri Schiavo made which do support their relief sought by her surrogate...include statements to him prompted by her grandmother being in intensive care that if she was ever a burden she would not want to live like that. Additionally, statements made to Michael Schiavo which were prompted by something on television regarding people on life support that she would not want to life [sic] like that also reflect her intention in this particular situation. Also, the statements she made in the presence of Scott Schiavo at the funeral luncheon for his grandmother that 'if I ever go like that just let me go. Don't leave me there. I don't want to be kept alive on a machine.' And to Joan Schiavo following a television movie in which a man following an accident was in a coma to the effect that she wanted it stated in her will that she would want the tubes and everything taken out if that ever happened to her are likewise reflective of this intent. The court specifically finds that these statements are Terri Schiavo's...and the testimony...is reliable, is creditable and rises to the level of clear and convincing evidence to this court.⁹

The Schindlers proceeded with several petitions, which prompted Judge Greer to issue a stay on his original order until 30 days beyond the final exhaustion of all appeals by the Schindlers. The Schindlers appealed to the Florida Second District Court of Appeal, which on January 24, 2001, upheld Judge Greer's original ruling permitting the removal of the PEG tube. Responding to the Schindlers' claim that clear and convincing evidence of Terri's wishes had not been produced during the original trial, the Second District Court of Appeal stated,

We have reviewed that testimony and conclude that the trial court had sufficient evidence to make this decision....Her statements to her friends and family about the dying process were few and they were oral. Nevertheless, those statements, along with other evidence about Theresa, gave the trial court a sufficient basis to make this decision for her....After due consideration, we conclude that the trial judge had clear and convincing evidence to answer this question as he did.¹²

Another aspect of the Second District Court of Appeal's opinion is their statement regarding the court's duties in cases in which a patient's intent or wishes are unknown: "In *Browning*, we stated: 'In making this difficult decision,

a surrogate decision-maker should err on the side of life....In cases of doubt, we must assume that a patient would choose to defend life in exercising his or her right of privacy.' We confirm today that a court's default position must favor life."¹³ (We subsequently discuss the importance of this decision and these statements in light of assertions by some that the judiciary supports euthanasia, has contempt for life, and as a result, promulgates a social agenda from the bench.)

Throughout the next few months, the Schindlers requested an Appellate Court rehearing and that Judge Greer recuse himself, as well as petitioned the Florida Supreme Court to stay the removal of the PEG tube, which had been scheduled to be removed on April 20, 2001. All requests and petitions were denied. However, on April 20, Federal District Court Judge Richard Lazzara granted a stay until April 23 to allow the Schindlers all possible attempts at appeal. An appeal was issued to the US Supreme Court, but on April 23, US Supreme Court Justice Anthony Kennedy refused to stay the case pending a formal review by that court. The PEG tube was removed on April 24.

Two days later, the Schindlers filed an emergency motion with Judge Greer claiming new evidence that Michael had perjured himself about Terri's wishes, the source being a former girlfriend of Michael's. When Judge Greer dismissed the motion as untimely, the Schindlers filed a civil suit against Michael, leading Circuit Court Judge Frank Quesada to order that the PEG tube be reinserted pending the trial. A series of appeals and court orders were exchanged to establish jurisdiction for the trial, and on August 7, 2001, Judge Greer once again found that the tube could be removed. However, Judge Greer delayed removal to allow the Schindlers time to appeal, and on October 3 the Second District Court of Appeal delayed removal of the PEG indefinitely.

On October 17, 2001, the Second District Court of Appeal ordered that 5 physicians examine Terri to determine whether her condition could improve with additional medical treatment. Michael and the Schindlers chose 2 physicians each, and the court selected 1 physician. However, the process was delayed for mediation to determine which tests physicians could perform on Terri. Mediation failed, and hearings involving the 5 physician witnesses and Terri's primary physician occurred October 12 through 22, 2002. The 2 physicians selected by the Schindlers stated that Terri was not in a PVS and that beneficial treatments were possible. However, neither physician was able to present factual documentation of the success in someone in Terri's condition of the treatments recommended (vasodilation therapy and hyperbaric oxygen treatments), and the court found that those recommendations

lacked credibility.¹⁴ The other 3 physicians concurred with previous medical evaluations that Terri was in a PVS with no chance of improvement. Notably, one of the physicians that Michael selected, although an expert in the area of PVS, was controversial in light of previous statements regarding the withholding or withdrawal of AFN from patients in a PVS. This physician's involvement inflamed members of the public who were becoming increasingly interested in and vocal about the case and who believed that withdrawing the PEG tube was akin to euthanasia. In response to these proceedings, the Schindlers rescinded their earlier acknowledgment that Terri was in a PVS. On November 15, 2002, the Schindlers filed another petition to remove Michael as guardian, this time not only claiming that he was neglecting and "abusing" Terri by providing inadequate care and rehabilitation but also suggesting that Michael may have been directly responsible for Terri's original injury through an act of physical abuse.¹⁵

On the basis of the medical testimony, Judge Greer again ruled that the PEG tube could be removed but stayed the ruling pending an appellate court challenge. The Second District Court of Appeal affirmed Greer's order, setting October 15, 2003, as the date for PEG tube removal. Throughout the next several months, there were multiple challenges and filings, including an appeal to the Florida Supreme Court (which declined to review the decision). Nevertheless, on October 15, the PEG tube was capped.

On October 19, 2003, the Advocacy Center for Persons with Disabilities filed a federal lawsuit claiming the cessation of AFN was abuse and neglect. Increasingly, groups representing persons with disabilities got involved with the case and expressed fears that what was happening to Terri was evidence of how the nondisabled society devalues persons with disabilities. On October 20, the Florida House of Representatives passed *Terri's Law*, which was passed the next day by the Florida Senate and signed by Governor Jeb Bush, who then immediately issued an executive order¹⁰ directing the reconnection of the PEG tube, which was done, and appointing a third guardian ad litem. *Terri's Law*, HB 35-E,¹⁶ was a brief statement authorizing a one-time stay for the specific prevention of withholding or withdrawing nutrition and hydration in a patient whose circumstances fit the unique situation of Terri. Also on that same day, Michael, joined by the American Civil Liberties Union, filed a state court lawsuit asserting that *Terri's Law* was unconstitutional. Ten days later, Jay Wolfson, DrPH, JD, was appointed as the third guardian ad litem.

Wolfson issued his report on December 1, 2003. During his term as guardian ad litem, Wolfson spent a large

amount of time with Terri, sometimes visiting her multiple times during a day. He reported,

During that time, the GAL [guardian ad litem] was not able to independently determine that there were consistent, repetitive, intentional, reproducible interactive and aware activities....Hours of observed video tape recordings of Theresa offer little objective insight about her awareness and interactive behaviors.¹³

He concluded,

...from the medical records and consultations with medical experts that the scope and weight of the medical information within the file concerning Theresa Schiavo consists of competent, well documented information that she is in a persistent vegetative state with no likelihood of improvement, and that the neurological and speech pathology evidence in the file support the contention that she cannot take oral nutrition or hydration and cannot consciously interact with her environment.¹³

Despite Wolfson's explicit articulation that the courts had meticulously followed Florida law and constitutional principles in arriving at their conclusions regarding Terri's wishes,¹³ Governor Jeb Bush rejected Wolfson's conclusions and Wolfson's recommendation that AFN be discontinued.¹⁷

Michael's legal challenge to *Terri's Law* culminated in the opinion of Pinellas Circuit Judge W. Douglas Baird, released on May 6, 2004, declaring that *Terri's Law* was unconstitutional, a clear violation of the separation of powers.¹⁸ Governor Bush appealed the ruling, which was then referred directly to the Florida Supreme Court. The Florida Supreme Court ruled unanimously to affirm Judge Baird's conclusions and declared *Terri's Law* unconstitutional on September 23, 2004.¹⁹ Governor Jeb Bush filed for rehearing and was denied twice, but the Florida Supreme Court ultimately stayed its order to remove the PEG tube pending an appeal by Governor Bush to the US Supreme Court. On January 24, 2005, the US Supreme Court refused to grant review. Judge Greer then gave permission for the PEG tube to be removed on March 18, and the tube was removed on that date. Petitions by the Schindlers to the Second District Court of Appeal, the Florida Supreme Court, and the US Supreme Court to intervene were denied.

The series of events that followed are unique in the history of American politics, law, and bioethics. On March 7, 2005, US Representative David Weldon of Florida introduced in the US House of Representatives H.R. 1151, the Incapacitated Person's Legal Protection Act,²⁰ which would allow federal judicial review of state court orders to withdraw or withhold AFN, with similar legislation also introduced in the US Senate. On March 20, with a voice vote of only 3 members present, the bill was passed in the

Senate. The House bill, by a vote of 203 to 58, was passed at 12:42 AM on March 21. President George W. Bush had been vacationing but returned early to Washington, DC, on March 20 to be available to sign the bill once passed, and he signed the bill at 1:11 AM.

Consequently, on March 22, Federal Judge James Whittemore denied a request to overturn Judge Greer's order. The following day, a 3-judge panel of the US 11th Circuit Court of Appeals reviewed and denied a similar request, and then the entire 12-judge court as a whole refused to hear the appeal. Governor Jeb Bush declared he wanted the Florida Department of Children and Families to take custody of Terri, but Judge Greer issued an order preventing this action. On March 24, the US Supreme Court declined a request to hear the case and overrule the 11th Circuit Court's decision. A federal judge in Tampa, Fla, and the Florida Supreme Court refused requests to intervene. On March 30, the 11th Circuit Court of Appeals was petitioned but rejected a request for a new hearing. Terri Schiavo died at age 41 years at 9:05 AM on March 31, 2005.

The autopsy report was released 2½ months after Terri's death.⁴ Dr Jon Thogmartin, Florida's District Six Medical Examiner, reported that the degree of brain damage Terri had sustained was severe and irreversible, and there was no hope of rehabilitation. Her brain weighed only 615 g, less than half that expected for a 41-year-old person and less than that of Karen Ann Quinlan, another young woman who, before her death, had been in a long-term PVS and like Terri Schiavo had been the focus of a widely publicized legal and ethical controversy regarding the withdrawal of a life-sustaining medical intervention (ie, a mechanical ventilator). Terri had sustained severe loss of the occipital cortex, leading the examiner to state that she was blind, thereby refuting claims that she was visually aware of her environment. Many areas of her brain were devoid of functional neurons and contained only supportive cells. Dr Thogmartin also stated that Terri would not have been able to hydrate or nourish herself by nonartificial means. One other finding is pertinent to the question of why magnetic resonance imaging (MRI) or functional MRI had not or could not have been performed to help establish more clearly Terri's level of brain function and diagnosis: the experimental thalamic implant was still in place. In these situations, some physicians avoid MRI studies because of concern of causing harm. Indeed, in May 2005, the Food and Drug Administration issued an advisory concerning reports of serious injury or death occurring in patients with implanted neurologic stimulators undergoing MRI procedures.²¹ Although the presence of the thalamic implant may not have been an absolute contraindication, it may have caused her physicians to

weigh carefully the risks vs how much additional information would be obtained of real value (in addition to the previous computed tomography imaging that revealed profound cerebral atrophy²²).

THE PRACTICAL QUESTIONS WE MUST ANSWER

IS IT ETHICALLY AND LEGALLY PERMISSIBLE TO WITHDRAW OR WITHHOLD LSTs?

The ethical principle of respect for patient autonomy (particularly the right to maintain bodily integrity and to be left alone) underlies the right of patients to refuse, or request the withdrawal of, unwanted medical interventions. Patients may decline interventions that they previously consented to if their health care values and goals have changed. Regardless of intent, physicians should not impose treatments on patients that patients do not want because doing so constitutes battery.²³

Indeed, from a legal standpoint, patients in the United States have a constitutionally recognized right to refuse any and all forms of medical intervention, whether or not they are terminal and whether or not such refusal may lead to their death. This acknowledged and protected freedom is the culmination of decades of cases, beginning in the 1960s with the recognition that Jehovah's Witnesses could refuse blood products, even if such refusal would lead to their death. The definitive statement of the right to refuse treatment was the US Supreme Court decision of *Cruzan v Director, Missouri Department of Health*. This case involved a dispute between the family of a young woman, who was in a PVS after an automobile crash and was sustained with a feeding tube, and the State of Missouri regarding whether the feeding tube could be removed. The family claimed that their daughter (after 5 years in a PVS with no hope of improvement) would not want to continue in her current state. The Missouri Supreme Court claimed that clear and convincing evidence of the patient's wishes must be presented before LSTs can be withheld or withdrawn and was skeptical that such evidence was present in this specific case.²⁴ The US Supreme Court found that states could adopt a clear and convincing evidentiary standard for withholding or withdrawing LSTs and affirmed that AFN was like any other medical intervention and could be refused or stopped once begun.²⁵ Today, states such as Missouri and Florida²⁶ require clear and convincing evidence for withholding or withdrawing LSTs if the patient is incapable of speaking.²⁷

In reference to the Terri Schiavo case and addressing the issue of the right to refuse treatment, 55 bioethicists stated, in an amicus curiae brief submitted to the Florida Supreme Court,

The implicated bioethical issue is not whether elderly or disabled persons can be deprived of wanted treatment, but how to implement their fundamental right to decline life-prolonging measures they would abhor. It is certainly true, as the Governor observes, that "the State has a compelling interest in ensuring that people with disabilities are not deprived of basic human rights"...but among those basic human rights is the right to refuse medical treatment. The Governor wants to deprive Terri Schiavo of that right, which the judicial process has determined she would want to exercise.²⁸

WHO SPEAKS FOR THE PATIENT WHEN THE PATIENT CANNOT SPEAK?

Physicians frequently care for patients who lack decision-making capacity and cannot speak on their own behalf. In these situations, physicians must rely on surrogates (also known as proxies) to make decisions for the patient. If the patient has an advance directive that names a surrogate, that choice should be respected. In fact, all 50 states and the District of Columbia have laws concerning the use of advance directives for preserving patient autonomy when the patient lacks decision-making capacity, either temporarily or permanently.²⁷ Unfortunately, most adult Americans, like Terri Schiavo, do not have an advance directive. In these situations, physicians must identify a legally authorized surrogate. Some states have statutes that specify a hierarchy of surrogates (eg, court-appointed guardian, followed by the spouse, an adult child, sibling, etc), whereas other states do not specify a formal hierarchy. The Schiavo case occurred in Florida, and therefore we must review the relevant laws for that state.

A key case influencing Florida's approach to the issue of surrogate decision making, one frequently referenced in the documents of the Schiavo case, is *In re Guardianship of Browning*.²⁶ In that case, the court declared, "An integral component of self determination is the right to make choices pertaining to one's health, including the right to refuse unwanted medical treatment...[A]n incompetent person has the same right to refuse medical treatment as a competent person." Establishing the validity of surrogate decision making to preserve the incompetent person's right to refuse treatment, the court nevertheless set the standard that surrogate decision makers must provide clear and convincing evidence to withdraw LSTs.

The sentiment and judicial requirements articulated in *Browning* were subsequently codified in the Florida statutes, Chapter 765 (FS 765), governing health care advance directives. Unlike some states, Florida has a clearly articulated hierarchy for establishing a health care proxy in the absence of a court- or advance directive-appointed surrogate. According to FS 765.401, if an incapacitated patient has not executed an advance directive or designated a surrogate to execute an advance directive, health care deci-

sions may be made for the patient by any of the following individuals, in the following order of priority: (1) judicially appointed surrogate, (2) the patient's spouse, (3) an adult child of the patient or majority of adult children, (4) a parent of the patient, (5) an adult sibling or majority of adult siblings, (6) an adult relative, or (7) a close friend of the patient.

The goal of this statute is to identify the individual(s) most likely to know the values, goals, and fears of the patient in order to best provide substituted judgment of what the patient would desire. In the Schiavo case, Michael was both her court-appointed guardian and her husband, the 2 highest ranking positions for selecting a proxy.

WHAT ARE THE DUTIES OF A SURROGATE DECISION MAKER OR PROXY?

First and foremost, a health care surrogate or proxy has the moral obligation to follow the explicit directives of the patient, as articulated formally in an advance directive or by complying with the patient's previously expressed wishes. In the absence of explicit instructions, surrogates must use "substituted judgment," that is, knowing the worldview, values, goals, and fears of the patient and making decisions as closely as possible to those the patient would make if capable. Often, these decisions are difficult. Families may not discuss end-of-life and similar issues, and as a result, surrogates may genuinely not know how the patient would decide. In these situations, the surrogate should follow the "best interest" standard, that is, given the medical facts and prognosis, make decisions that would be in the best interests of the patient. Although each subsequent standard is less directed by the patient's known wishes and beliefs, when those wishes and beliefs are known, the surrogate is obligated to execute them. Specifically, Florida FS 765 states,

Before exercising the incapacitated patient's rights to select or decline health care,...a proxy's decision to withhold or withdraw life-prolonging procedures must be supported by clear and convincing evidence that the decision would have been the one the patient would have chosen had the patient been competent or, if there is no indication of what the patient would have chosen, that the decision is in the patient's best interest.²⁹

Consequently, when the Schindlers testified in their depositions that, if they were to act as Terri's surrogate decision maker, they would insist on maintaining the feeding tube and all life support even if Terri had left written instructions to the contrary,¹⁰ they disqualified themselves from ever being appointed proxies. Despite the Schindlers' own perceived good intentions, no judge could grant

them responsibility for Terri's care because they had declared that they would ignore the fundamental ethical and legal requirements of a proper surrogate.

WHAT SHOULD BE DONE WHEN IT IS SUSPECTED THAT A SURROGATE MAY NOT BE ACTING IN THE BEST INTERESTS OF THE PATIENT?

Despite the authority of surrogate decision makers to speak on behalf of patients, the ethical principle of beneficence requires that physicians act as their patients' advocates. If it appears that a proxy is not making decisions in the best interests of the patient, the physician can act by invoking statutes that protect vulnerable adults, where they exist, and appear in court requesting the appointment of another health care surrogate.

In the case of Terri Schiavo, it was the Schindlers who questioned the appropriateness of Michael as Terri's surrogate and sought a court-appointed change of Terri's surrogate. However, the courts consistently found that Michael had been acting properly as Terri's surrogate on 2 accounts: (1) he reflected her previously expressed wishes and views about LSTs, and (2) he acted in her best interests. Although controversy regarding the latter account continues, it is important to note the courts' inclination to protect the former. In the landmark *Wanglie* decision,^{30,31} which brought the question of so-called medical futility into the bioethical and medical limelight, the court found that the most important fact was that the patient's legally recognized surrogate, her husband, was following the previously expressed wishes of the patient. Helga Wanglie was an elderly woman with severe lung disease who sustained a fractured hip. Her medical course was complex, and she lapsed into a PVS and required mechanical ventilation. The treating physicians believed that continuing LSTs was not beneficial to Mrs Wanglie because she had no hope of regaining consciousness. However, her husband, appointed by her advance directive as her surrogate, stated that she had always instructed him to never give up on her and to maintain her life as long as possible; therefore, he could not consent to the recommendation to withdraw ventilatory support. The patient's children corroborated the husband's statements concerning their mother's wishes. The hospital went to court to have Mr Wanglie replaced by a court-appointed surrogate who would better make decisions in the patient's best interests. The court ruled on behalf of Mr Wanglie, stating that he was acting competently as Mrs Wanglie's surrogate by making sure that her wishes were followed.

In general, courts want to stay out of these kinds of disputes. As much as possible, they try to discern what the patient would want and protect those wishes. Beyond that, as Judge Greer and the Second District Court of Appeal

clearly stated, the courts try to err on the side of protecting life. However, all the courts involved in the Schiavo case believed that clear and convincing evidence had been provided for what Terri would want. Finding that Michael's requests were in keeping with Terri's wishes, unless confronted with clear evidence that he was not representing her wishes or not acting in her best interests, the courts would have been negligent in their duties to have acted other than they did (ie, acting in a manner contrary to established principles of ethics, state and federal law, and legal precedence).

IS AFN A MEDICAL TREATMENT OR MANDATORY COMFORT CARE?

This question was one of the primary issues debated at the time of the *Cruzan*²⁵ decision and during the Schiavo case. It remains a contested issue in our society. From a legal perspective, the issue was resolved with *Cruzan*. From medical and practical perspectives, we believe it should be clear as well. Throughout the history of medical ethics, questions about what should be considered mandatory care have surfaced; therefore, we submit an approach to the question, "What is a medical intervention?" that can be used not only for AFN but also for other interventions. We call this test the "Little House on the Prairie Test." This test simply asks that one envision being with Dr Hiram Baker in Walnut Grove, Minn, in the 1880s and confronted with a patient similar to Terri Schiavo. If the patient has a pathologic condition such that Dr Baker could not maintain the patient's life with the available treatments (which were little more than comfort care measures), then the patient had a life-threatening illness or lethal pathologic condition beyond the efficacy of humane care. Terri had a life-threatening pathologic condition that rendered her unable to hydrate and nourish herself even by hand-feeding or using a baby's bottle. Instead, Terri needed a PEG tube, which required endoscopy or a surgical procedure to insert. Notably, the skills and technology required to place a PEG tube have been available for only several decades, and the pre-prepared nutritional formulas infused via the tube require the oversight of an experienced nutritionist. Therefore, that which was required to sustain her was beyond the level of humane or comfort care; it was a medical intervention. Using the Little House on the Prairie Test, Terri's feeding tube is a medical treatment that she had the right to refuse, either directly or through a surrogate. The claims that she was forcibly starved and dehydrated, tortured, and denied humane treatment are untrue. Terri was not in a room where she was prohibited from accessing food; she had a pathologic condition (severe cerebral injury and atrophy) that would inevitably cause her to die without *medical* intervention. Artificially supplied fluid and nutrition is no different than dialysis, mechanical ventilation, pacemak-

ers,³² and other medical treatments that bypass lesions and other pathologic conditions that prevent normal physiological and anatomical functions. Artificially supplied fluid and nutrition, or any medical treatment, can be withheld and/or withdrawn when it is determined to be unwanted by the patient or incapable of leading to the desired goals of medical treatment in general, such as the restoration of function and independent living.

On the floor of the House of Representatives, Representative Dave Weldon (Florida), a physician, stated, "Terri is not on life support. She is not dying of an underlying disease...." Dr Weldon was in error. Terri was on life support, demonstrated very clearly by the fact that she died after a medical intervention, AFN, was discontinued, and her caregivers were unable to keep her alive without this intervention. Medical interventions are foreign to the human body, they are not an intrinsic part of it, as evidenced by the fact that most people get along well without a physician's assistance until they have an illness or injury. It is presumptuous and a disservice to our patients and profession when we insist that our interventions be seen as mandatory. Beneficial as they may be, medical interventions are not the essence of life itself. Once the physician, and any nonmedical voice, insists that treatments are mandatory in all circumstances, medicine becomes less a servant of humankind and more a master.

Even though AFN is a medical treatment, we acknowledge that there are strong emotional, even visceral, responses to the thought of denying a patient "food and water." Food is an important part of all human activities and cultures. "Food is love." We celebrate the most important events in our lives—births, birthdays, marriage, deaths, religious and maturational milestones—around meals. As a result, many regard AFN as different from other medical treatments. Physicians should endeavor to understand and address these emotional responses by informing patients, family members, and surrogates of the distinction between food and water shared and consumed by those who eat and drink, and AFN, a medical treatment.

ARE FEEDING TUBES FREE OF RISK AND OTHERWISE BENIGN INTERVENTIONS?

Given the fact that the father of one of the authors (C.C.H.) died of complications of a feeding tube (bowel perforation and subsequent peritonitis and septic shock), the immediate answer is: not necessarily. Although this is an extraordinary example of the potential risk of feeding tubes, data show that feeding tubes, like any medical intervention, have associated risks. In fact, approximately 11% of patients with PEG tubes experience complications due to the tube in the long-term.^{33,34} Nevertheless, during the Schiavo controversy, some individuals claimed that PEGs are com-

pletely benign interventions. Although it is true that Terri was doing well physically with her PEG tube, the harm of imposing treatments on patients should not be discounted. All medical interventions have consequences, and hence the goals of the interventions must be clearly considered and the interventions must be appropriate for achieving those goals.³⁵

DOES THE PATIENT'S DIAGNOSIS MAKE A DIFFERENCE IN THE DECISION TO WITHDRAW OR WITHHOLD MEDICAL TREATMENTS?

The media paid substantial attention to Terri's diagnosis (eg, PVS vs minimally conscious state). In reality, diagnosis in and of itself is irrelevant. If the patient's wishes are known, as they were considered to be in this case, that is the relevant factor in determining the course of treatment. Regardless, it was universally confirmed, at least by physicians who did not have a proprietary conflict of interest, that the chances of Terri's level of consciousness improving to a point at which she could be considered capable and competent to provide additional views on continuing or discontinuing the feeding tube were nil, opinions corroborated by the autopsy findings. However, making efforts to better establish a diagnosis would be relevant if in doing so the patient might be able to better communicate his or her wishes.

IS TERMINAL DEHYDRATION PAINFUL?

Among the most notable factual errors circulated during the Schiavo controversy were the descriptions of the consequences of withdrawing AFN. For example, on October 21, 2003, on the floor of the House of Representatives, Representative Joe Pitts declared,

Mr. Speaker, death by dehydration is a painful, agonizing, and arduous process....In addition to feeling pangs of hunger and thirst, the skin, lips, and tongue crack, the nose bleeds because of the drying of mucous membranes, heaving and vomiting may ensue because of the drying out of the stomach lining, and the victim may experience seizures. Compared to starvation and dehydration, death by hanging, firing squad, or even the electric chair seems humane.

Besides denying the fact that hundreds of individuals die each year in the United States after forgoing AFN without the symptoms described in the preceding quote, the statements are simply untrue. Studies have found that most debilitated patients do not experience much thirst or hunger when AFN is discontinued, and if they do, these symptoms are transient and easily alleviated with simple local measures.³⁶ Other studies have concluded that patients who forgo AFN typically experience comfortable deaths.^{37,38} Still other studies have reported that AFN does not neces-

sarily relieve thirst in alert terminally ill patients, showing that thirst may not necessarily correlate with physiological parameters of hydration.³⁹ Notably, a central principle of palliative and hospice care is that withholding or withdrawing AFN (or any LST) does not mean that good oral care, bathing, pain control, and other comfort measures will be discontinued as well. Rather, excellent palliative care requires scrupulous attention to these issues.

In our opinion, this question is a good illustration of one failure of the media in its reporting during the Schiavo controversy. Statements like the one made by Representative Pitts were unchallenged. Of all the voices engaged in the Schiavo debate, few belonged to physicians who could authoritatively and accurately speak to the medical issues. Indeed, we believe the press missed an excellent opportunity to educate and inform the general public on matters related to advance directives, surrogate decision making, AFN, and end-of-life care.

IS WITHHOLDING OR WITHDRAWING AFN THE SAME AS EUTHANASIA?

Another claim made during the Schiavo controversy was that Michael and the State of Florida were overtly killing Terri as an act of euthanasia by withdrawing the feeding tube. As we have discussed, from ethical and legal standpoints, this claim is not true. Her underlying pathologic condition, which prevented her from hydrating and nourishing herself without the assistance of an external medical intervention, was the cause of her death. However, the contention that withholding or withdrawing LSTs and euthanasia are the same is held by many. The decision to limit LSTs may lead to death, but it is a different kind of choice from euthanasia. Refusing LSTs is a request to be left alone, the goal of which is to be free of burdensome and unwanted medical treatments and to allow nature to take its course. Euthanasia is a deliberate act, the goal of which is to kill the patient. In euthanasia, a human being, not a disease, is the final arbiter of death.

Chief Justice William Rehnquist, writing for the majority of the US Supreme Court in the case of *Vacco v Quill*, made clear the legal distinction between withdrawing or withholding unwanted medical interventions and euthanasia:

The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication...[In *Cruzan*] our assumption of a right to refuse treatment was grounded not...on the proposition that patients have a general and abstract "right to hasten death," but on well established, traditional rights to bodily integrity and freedom from unwanted touching.⁴⁰

IS THERE A BETTER WAY?

We hope that by this point readers understand that due process was followed in the case of Terri Schiavo. In fact, the courts appear to have carefully considered all the claims of Michael (most notably through the appointment of 3 guardian ad litem) and extended the Schindlers every possible opportunity to appeal. We hope that readers understand the real legal issues that the court faced and that they were met with due diligence and comported with the requirements of the law. We also hope that it is clear that the courts were not making judgments on the value of Terri's life, but rather doing their best to honor her life by trying to seek out and comply with her previously expressed wishes. Terri's life was indeed precious, no matter how debilitated, and her "worth" was not in question. The unfortunate reality for each of us is that we are mortal, subject to injury, and, ultimately, pathology and death will rule the day. Each of us must face this reality and determine the appropriate levels of medical intervention that each is willing to undergo in forestalling the inevitable. We live in a time when medical knowledge and power can prolong life in a variety of disease states that cause severe debilitation, and our technical abilities often challenge our wisdom about appropriate implementation.

Furthermore, we must acknowledge our ignorance in many areas. Prognosis is as much an art as evidence based, and uncertainty afflicts our attempts at decision making. Ours is a pluralistic society filled with heterogeneous belief systems, with many varied and often conflicting views about the value and goals of life, the nature of life and death, and the extent of our ethical and technical obligations to preserve life. In the context of the Terri Schiavo case, we therefore must ask the question, "Is ours the best system possible to respond to such a case in light of all the diversity in our society?"

As was illustrated in the proceedings of the case, the system declared the case was based on 2 sometimes conflicting principles: (1) the value of human life, and the default position to preserve it, and (2) the value of an individual's freedom to govern his or her life as much as possible without harming others. In the case of conflict between those 2 principles, the second has precedence in order to prevent the imprisonment of patients by treatments they do not want or that may not coincide with their worldview. Many expressed disagreement with this position, claiming that the first principle, the preserving of life regardless of circumstances or beliefs, must predominate. However, if the first principle predominated, it would likely result in widespread violation of the beliefs and values of many patients (many of whom consider themselves pro-life) who are unwilling to raise mere biological life to the level of the highest of all values or considerations

(eg, in priority over spiritual or ultimate concerns) or who more easily accept death as a natural part of the human journey. The current system allows and protects both those who would want ongoing LST by its default presumption for the preservation of life (and would protect any advance directive that requested full life support) and those who would limit such support. If Terri had not made statements indicating her preference to limit LSTs or had expressed a desire to receive LSTs, then the system would have maintained the AFN.

One can predict, however, in response to the Schiavo case that many state legislatures will pursue legislation to roll back freedoms to refuse or request the withdrawal of unwanted medical interventions. In fact, we are aware of initiatives in some states to mandate that all patients receive AFN unless there is an explicit written advance directive to the contrary.⁴¹⁻⁴³ However, these same states are not providing the resources necessary to adequately educate the public about these issues or to facilitate means to encourage citizens to prepare appropriate expressions of their desires to be free of unwanted medical intervention (eg, through advance directives).

The profession of medicine should oppose measures that will unreasonably tie our hands and those of our patients. For example, to demand that we impose unwanted treatments on a patient for whom there is no prospect of improvement, who has left verbal information expressing his or her life and health care values and goals but did not take the time to or could not complete an advance directive (like most Americans), is unconscionable and violates the oldest of ethical principles—non-maleficence, or do no harm. Although surrogate decision making is imperfect (eg, surrogates do not always know what a patient might want), the surrogate is still more likely to know the patient's values and wishes better than others, including physicians, judges, and legislators. President George W. Bush stated during the Schiavo saga, "The essence of civilization is that the strong have a duty to protect the weak." Indeed, this statement is true and requires protecting the rights of vulnerable persons to express their values and life goals and have those wishes respected without undue bureaucratic obstruction or burdens.

LESSONS LEARNED: HOW SHOULD WE RESPOND?

We should learn many lessons from this case. The medical profession must become more prominent and proactive in educating their patients and the public about health care and health care ethics, particularly given the great expansion of health care information and advances. It is our responsibility as trustees of the public health and as advocates for our patients' best interests. On its own, the con-

temporary press is unable to perform this duty. Thus, medical organizations should provide more than just spokespersons to media outlets. Each physician should be more interested and involved in patient and public education on these matters. In addition, physicians should be more willing to engage in the political process. As mentioned previously, some state legislatures will respond to the Schiavo case by pursuing legislation that will limit patient rights. The familiar adage is unfortunately true: hard cases make bad law. Too much is at stake for us to just stand by. We should try to engage in positive and constructive ways, offering our expertise to advise our local representatives and serve the legislatures as consultants.

We need to take seriously the expressions of fear from persons with disabilities. Tragically, the Schiavo case illustrated that many disabled persons feel devalued, marginalized, and threatened in our society. We need to hear this message, and as healers, those who care and advocate for disabled persons, we need to more actively engage in promoting their concerns and acceptance.

We also need to be more effective in facilitating the preparation of advance directives for ourselves and our patients. More importantly, we need to facilitate discussions between patients and their surrogates and other family members about medical issues, particularly LSTs. Physicians need to take the time to discuss with patients their health care goals, fears, beliefs, and wishes. Physicians should document these discussions. We need to ensure that advance directives are competent, that is, that they are based on truly informed consent and refusal and that they accurately reflect the desires of our patients. If nothing else, the Schiavo case demonstrates that these issues are best dealt with privately, within families and between the patient and his or her caregivers. Even in the best situations, legal due process cannot prevent things from getting out of control. To the degree that we can preempt such disputes, we should use all means.

The long saga of Terri Schiavo was a genuine tragedy. In respect for her, and for all who may be so afflicted, it is our duty to learn from this saga and respond in the most constructive means possible. We must strive to objectively review the facts of this case and similar cases of profound neurologic impairment so that healing can begin. Ignorance of key ethical, legal, and medical realities was the main fuel to the fires of this controversy. However, this ignorance, perpetuated by inadequate reporting, political figures, and an all too quiet medical profession, has not only deepened divisions within our society but also dehumanized a young woman, turning her more into a symbol than the person she was. As a profession, we

owe it to Terri Schiavo to do everything we can to learn the lessons of her story.

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